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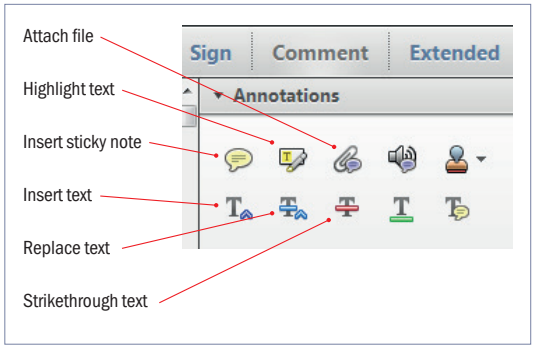

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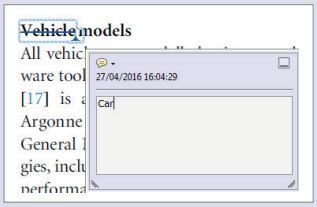

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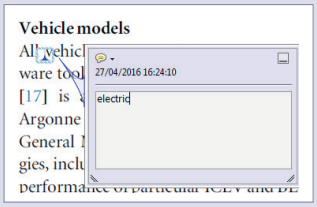

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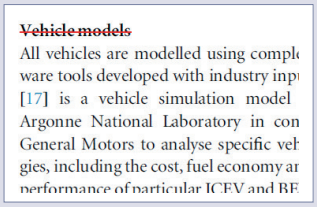

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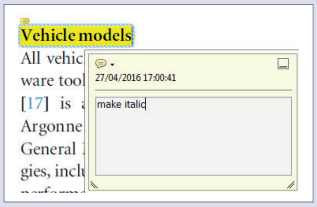

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research

Making use of evidence in commissioning practice: insights into the understanding of a telecare study's findings

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Introduction

In less than a generation, telecare has become a significant new resource for local authority (LA) Adult Social Care Departments (ASCDs) in England and other European countries to offer to people eligible for social care and support. All English ASCDs either have directly managed, or commissioned, telecare services, and telecare is often used as a 'first-line' service (that is, before other forms of intervention). The Whole System Demonstrator Project (WSD), a very large clinical trial funded by the English Department of Health (DH) concluded that it does not deliver better outcomes. Despite this, and in the context of unprecedented reductions in adult social care expenditure over the last decade (Innes and Tetlow, 2015), investment in telecare has continued in the UK. This article explores the extent and nature of the evidence used in LAs to support investment in telecare.

Background

Growth in the proportion of older people in the general populations of most European countries (Organisation for Economic Co-operation and Development, 2017) is

fostering interest in telecare and Assistive Technology (AT) (Milligan et al, 2011). Early UK telecare evaluations, along with telecare industry lobbying, contributed to telecare policy guidance from the DH (DH, 2005). This promoted 'scaling-up' of telecare use in publicly funded social care services. Central government funding of £80m was made available as a Preventative Technology Grant (PTG) to build local capacity and stimulate the use of telecare by ASCDs (DH, 2006). Performance indicators encouraged ASCDs to work with service providers and suppliers to rapidly install telecare in eligible people's homes.

The DH acknowledged shortcomings in the evidence available to underpin its telecare policy. Early studies had reported positive outcomes (Woolham, 2005; Alaszewski and Cappello, 2006; Bowes and McColgan, 2006), but most were small-scale, often methodologically flawed, and offered limited generalisability. To remedy this, the DH commissioned the Whole System Demonstrator (WSD) project to gain more robust evidence about outcomes (Bower et al, 2011). Data were collected from three English 'demonstrator sites', in which 5,806 people were randomly assigned to telecare or telehealth 'arms' and, within each, randomly, to intervention or control groups. The trial focused on people with long-term conditions: chronic obstructive pulmonary disease, heart failure, diabetes and adults with health and social care needs at risk of hospital admission. Within the telecare arm around 80% of participants were >65 years.

The DH published 'Headline Findings' from the trial before the study ended and before any papers were published (DH, 2011), and there was a clear assumption that it would validate existing policy guidance:

> The Whole System Demonstrator programme was set up by the Department of Health to show just what telehealth and telecare is capable of. To provide a clear evidence base to support important investment decisions and show how the technology supports people to live independently, take control and be responsible for their own health and care. (DH, 2011: 2)

These early findings may have been released to provide evidential support for a concordat between DH and the telecare industry in 2012. This called for rapid upscaling of telecare in the 'Three Million Lives' campaign and went further:

> The Whole System Demonstrator programme, a randomised control trial funded and run by the Department of Health, demonstrates how system changes alongside assistive technology can achieve a better quality of care for people living with long term conditions and social care needs. (DH, 2012a: 2)

Findings published by the research team told a different story. Those from the telehealth arm were positive (though not cost-effective), but there was no evidence that telecare users achieved significantly better outcomes. None of 16 measured outcomes showed any statistically significant difference between the two groups. The conclusion was clear:

> In this trial, telecare did not significantly alter rates of health or social care service use or mortality over 12 months (Steventon et al, 2013: 507).

Ettelt, Mays and Allen (2015) draw attention to tensions between researchers and policy makers occurring in three major evaluations of new approaches to care service delivery, including the WSD. In each evaluation the authors offer evidence to suggest that policy makers perceived the role of these studies as offering evidence in support of policy directions already established. The present paper, which focuses on perceptions of the WSD by local authority telecare managers, suggests that, in addition, these perceptions may have been shaped to some extent by telecare manufacturers and suppliers who played a leading role in offering operational guidance to these managers.

Responses to the WSD

Despite evidence that telecare use was not cost-effective, Department of Health policy was not amended. Additionally, the Association of Directors of Adult Social Services (ADASS) (ADASS, 2014: 2015) continued to promote telecare use – in collaboration with a leading telecare manufacturer, Tunstall PLC, a senior manager from this company writing some of the guidance provided on its website (Tunstall PLC was also an ADASS sponsor). Telecare continued to be seen as essential to meet increasing demand with shrinking resources, because of claims about its ability to reduce costs (ADASS, 2015). The ADASS model for creating and spreading telecare innovations is:

> … to allow councils to share practice and case studies to sustain and accelerate momentum in the use of technology in meeting improved health and wellbeing outcomes (ADASS, 2015: 2).

ADASS also launched a call for evidence from local authorities that produced case study examples of 'innovative' approaches to develop the use of telecare. However, the evidence to support the effectiveness of the interventions listed was generally descriptive case studies, usually not formal evaluations and, where evidence *was* provided, this was often based on low numbers, limited or no information about how samples were established or what research methods were used. No mention of final WSD findings was made in this 2015 report.

The context for this paper can therefore be briefly summarised. Evidence of telecare's impact in England, from a study described as generalisable (Steventon et al, 2015), concluded that outcomes were not significantly different from those receiving 'usual care'. There was no reappraisal of its value by ASCDs, which continued to implement telecare according to unchanged DH policy requirements. In the context of very reduced public expenditure overall this was an area of growth: for example, £20m in Hampshire (Sourcingfocus.com, 2014), £14m in Birmingham City Council area (Chartered Institute of Housing, 2012; Smith and Tomlinson, 2013), £2m in Hertfordshire (MacBeath, 2013), and £2m in North Yorkshire (Tunstall Healthcare Limited, 2009). Evidence, of a different form, to support ASCD telecare development was later published by ADASS. This raises the question of how WSD findings were appraised in LAs, if indeed telecare managers were aware of them, and if any wider observations can be made about the use of evidence in commissioning practice.

Aims and objectives

The aim of this paper is to explore how English ASCDs responded to the WSD findings and why they continued to invest in telecare despite evidence which concluded that it did not deliver better outcomes for recipients.

Methods

We undertook a mixed-method, prospective study, ~~*(anonymised for review)*~~ .The focus on older people was because they are the largest group of social care users, whose care costs dominate the adult social care budget and who are most likely to receive telecare services. AQ2

Telecare is often described in England as devices 'intended to compensate for or alleviate an injury, handicap or illness, or to replace a physical function' (Gov.uk, 2017). In this paper, we focus on both technology and the service infrastructure needed to make it work. We refer to 'standalone' devices (devices not linked to a monitoring centre) as 'electronic assistive technology' (AT). Devices which are call-centre linked are described as 'telecare'. Telehealth, which is not the focus of this paper, differs from telecare and refers to the use of vital signs technology (to collect data on blood pressure, pulse, temperature and so on) which is sent to a clinician remotely for interpretation and action.

Data collection had three stages. The first was a single telephone interview with a sample of 27 managers with overall responsibility for telecare services in 25 LAs. The second comprised 20 interviews with telecare commissioners, assessors, installers and responders in four case study sites – selected from stage one interviews because they afforded contrasting approaches to telecare service delivery.

The third was an electronic survey of LA telecare managers or equivalent. This paper draws only on data from this electronic survey, because many of the managers interviewed in the stage one interviews answered the same questions in the electronic survey, and the topic was not covered in stage two interviews. The survey was launched in November 2015 and closed in January 2016. Prior to launch, research team members publicised the prospective survey in the 'trade media' such as Community Care online and conferences attended by LA managers, including a presentation at a National Children and Adult Services (NCAS) attended by Local Authority Directors. Where possible, an email was sent directly to a named telecare manager in all English LAs (n=152) but if none could be identified, one was sent to the ASCD Director requesting them to forward it as appropriate for response. A single reminder was sent three weeks later. The survey consisted of 58 questions of which 11 were open format, in 12 sections, and used 'Surveymonkey' software, from which data were downloaded into SPSS v.23 for further analysis. Qualitative data from the 'open' survey questions was thematically analysed using 'Framework' analysis (Ritchie and Spencer, 1994).

An Advisory Group reviewed all aspects of the study. Advisors comprised representatives from ADASS, Age UK, Skills for Care, the telecare industry, an Occupational Therapist, an older service user and a family carer.

Findings

The final response to the survey was 114 (75%); 42 responses were excluded because they did not meet criteria (for example, responses from other UK nations, private individuals or telecare companies unless commissioned by a LA to provide a telecare service).

The survey included questions focused on awareness and use of research evidence in general, and knowledge of the WSD in particular. The first was a closed format question (see Figure 1).

Respondents were then asked if they knew about the findings of WSD (see Figure 2). As Figure 2 shows, almost two-thirds of respondents said they were aware of WSD findings. For this group, a follow-up question: 'If you answered "yes" to the last question, do you have any opinions about findings from the Whole System Demonstrator project?' was included. 69 of the 71 respondents to the earlier question replied. Thematic analysis of responses suggested that respondents held negative opinions about the WSD. Comments focused on both methods and findings.

Several criticisms of the WSD **methods** were made. Some raised unspecified concerns about the quality of the study:

> There are questions over the methodology used and how scientifically robust the trials were. (LA16)

Others were more specific, suggesting that the trial design was unrealistic and failed to capture the true impact of telecare, and a more holistic approach was needed:

> The findings of the WSD do seem to be counter-intuitive and I have heard some comments that the trial was designed by academics who did not reflect a 'real world' approach… (LA62)
>
> Unfortunately, due to the methodology of the WSD it produced findings and results which were not reflective of local service delivery. For example, costs of delivery were skewed because of the high cost of implementing the trials. The WSD project had a negative impact… (LA75)

Some also argued that the *rigour* of the study was a weakness:

> The WSD was too rigid in its framework and requirements to participate, therefore becoming unrealistic. Its failure to be flexible meant that the participants weren't able to gain the full benefit from the equipment and the potential financial benefits remained undiscovered. (LA32)

Figure 1: Broadly speaking, would you say telecare in your Local Authority is informed by research evidence?

	n	%
Yes	51	45
No	37	33
Not sure	16	14
Not answered	10	9
Total	114	100

Figure 2: Are you aware of the findings of the Whole System Demonstrator Project? (The WSD was funded by the Department of Health. The research used a randomised controlled trial in three sites and produced robust data. Findings suggested that telecare did not produce better outcomes for people who used it. It did not offer a clear explanation of why the findings were negative).

	n	%
Yes	71	62
No	28	25
Not sure	4	4
Not answered	11	10
Total	114	100

Others argued that the choice of health conditions used to determine trial eligibility were suited more to telehealth than telecare, and that problems with the samples (the exclusion of some groups because of eligibility criteria and self-exclusion of others) were problematic. The complexity of the trial methodology was criticised and the difficulties of focusing on both telecare and telehealth in the three trial sites was one manifestation of this. Others felt the equipment used in the sites was obsolete, and that there had been a failure to agree stakeholder goals from the outset. Finally, some respondents felt that the trial had not adopted a person-centred approach and that this had led to inadequate assessments and training.

Interpretation of **findings** was also diverse. Some argued that these had demonstrated the positive benefits of telecare:

> … it showed that telecare can have a major impact on how services are being delivered. (LA16)
>
> Recollection of information about the WSD provided at the end of the project is that the results were positive. (LA17)

Other respondents felt that the WSD findings contradicted their own experiences of seeing telecare in use, and that the study overlooked the lived experience of telecare users and carers:

> Its findings do not tally with what customers and carers/friends tell us about telecare. (LA56)
>
> I'm broadly aware of the WSD research but wasn't aware it concluded telecare doesn't provide better outcomes. This conclusion is very different from our own experience. I recall the WSD findings were delayed but led to the '3 Million Lives' campaign led by the DH. Not sure why DH would want to expand use of telehealth and telecare if their research showed it didn't work! (LA25)
>
> I think (the findings) are quite questionable, and not particularly trusted either within telecare organisations/providers, or externally. (LA49)

There was also a sense of disappointment expressed by some respondents that the WSD had overlooked what they considered self-evident:

> I felt that the outcomes were disappointing and missed an important opportunity to look at the positive side of telecare provision. (LA95)

Discussion

The findings illustrate the range of perspectives held about the WSD, almost all negative. There was widespread distrust of the quality and 'trustworthiness' of its findings. In this section, these perspectives will be critically examined and located within wider literature. It is not the purpose of the paper to defend the WSD but to consider factors that affected what counted as evidence and how it was interpreted.

Perceived limitations of design and methodology

It is unclear to what extent control over the focus of the study rested with the WSD research team. Greenhalgh (2012) has drawn attention to a lack of clarity over the degree of DH involvement. Though WSD researchers described limited involvement of the DH in the project design and fieldwork, she suggests that the DH itself made 'greater claims' for its involvement in the 2012 Concordat (DH, 2012a), in which it suggested that its involvement extended to having 'funded and run' the trial (DH, 2012a). Though the level of involvement was unclear, what was apparent was a requirement that the study should be rigorous.

Recruitment criteria

The process of recruiting to the trial took long time, and was complex (DH, 2012b). The identification of participants from GP (family doctor) caseloads, the processes of obtaining informed consent and obtaining patient care and health records were necessary but may also have meant less time to follow-up. The WSD team acknowledged difficulty in assigning people to telecare or telehealth groups in view of the overlapping nature of their needs. Follow-up, of just 12 months, might also have been insufficient for telecare to have produced measurably different outcomes (Hirani et al, 2014). Follow-up time, along with the deployment of technology to a proportion of participants whose level of disability could have been less severe, may have made it more likely that outcomes would be non-significant. Arguably, too, some of the eligibility criteria were less than clear and required subjective judgements by care professionals and clinicians supporting the trial (for example, to determine if people were at risk of hospitalisation, and how disabling heart disease, COPD or diabetes were).

Use of 'old' technology

The trial was also concerned with 'usual telecare deployment' since it asked each site 'to design and procure their own telecare systems' (Steventon et al, 2013: 502). Tunstall PLC provided all the devices used in the three sites. Assessment for telecare or telehealth, and decisions about what technology to use were for local sites to determine. This increases the possibility of poor matching of technology with need (Milligan, 2011; Pols and Willems, 2011; Greenhalgh et al, 2013; 2015; Sugarhood AQ3

et al, 2014), and a risk of encouraging the use of substitute technologies that do not fully address the needs, or problems, identified (Gibson et al, 2015; 2016).

Non-person-centred approach to assessment

The trial intervention description offered a list of telecare devices used in the intervention arm (Bower et al, 2011), but not *how or why specific* telecare devices were deployed. Given that assessment and deployment of devices were left to local sites, any lack of person-centredness would not have been something WSD researchers could have addressed. The matching of technology to need through assessment, or the provision of information and the degree of involvement of telecare recipients in decisions about technology deployment, is under-researched, but likely to be extremely important in achieving good outcomes (Wey, 2004; 2006; Wherton and Monk, 2008; Pols and Willems, 2011; Greenhalgh et al, 2013; 2015; 2016; Johnston et al, 2014) and reducing risk of disappointment and technology abandonment (AKTIVE Consortium, 2013; Gramstad et al, 2014; Berge, 2016; Federici et al, 2016).

Lack of scientific robustness

Respondents who made this claim did not support it with examples or evidence. It is usually acknowledged that for clearly-defined research questions, ~~RCTs~~ are a more appropriate design to achieve 'generalisable' findings and to generate the most 'robust' type of evidence (Guyatt et al, 1995). However, some reject the widely held concept of a 'hierarchy' of evidence (Pawson et al, 2003), and RCTs do suffer from methodological shortcomings. For example, Kraus (2018) describes a range of assumptions, biases and limitations embedded in the ten 'most cited' RCT papers worldwide, and that bias can be an insoluble problem because attending to one form of bias can sometimes introduce bias of another kind. Nonetheless, Krauss suggests that biased RCTs can still be adequate to inform decisions, though cautioning against using single studies to inform policy. A problem for policy makers working in this area, however, was the absence of other rigorously-designed studies of telecare effectiveness (Barlow et al, 2007) which made meta-review impossible. WSD researchers were asked to answer a clearly-defined question for which an RCT was arguably the most suitable design, and more likely to produce generalisable findings. They were not responsible for how their findings would be interpreted and used (or not).

AQ4

Lack of 'realism' and need for more holistic approach to evaluation

RCTs do not always explore *why* a given intervention may or may not work unless a process evaluation is incorporated (Robson, 2002; Creswell, 2013). Though the WSD did publish a process evaluation (Hendy et al, 2012), which described issues relating to the completion of the trial, it did not 'explain' the findings. Concern was expressed by local sites that the WSD ignored pre-existing good practice and argued strongly for a more 'ecological' focus). Despite its size, and robust design, the WSD was criticised for ignoring pre-existing 'good practice' in the three sites in favour of a rigorous RCT by one of the LA staff responsible for telecare in one of the sites (Lowe, 2013a; 2013b). However, the WSD team was directed to produce rigorous findings by the DH. This

appeared to have been fuelled by concerns about scepticism among clinicians about the value of evidence not produced via an RCT (Clark and Goodwin, 2010: 10).

From the range of criticisms made of the WSD design and methods, some appeared to be based on inaccurate information about the trial, and others ignored or were unaware of the wider 'political' and policy context that shaped it. Other criticisms were echoed in some of the WSD team's own descriptions of their research's limitations.

Perceptions about WSD findings

Inaccurate beliefs about the findings

The understanding some participants had of the WSD findings was incorrect, and others said they had been surprised to learn from our online survey that the findings were not what they had originally thought. It is highly unlikely that telecare managers would have access to or wish to access the journals in which the findings were published or that they would read the (304-page) full report (Newman et al, 2014). It is therefore reasonable to assume that most may have derived their views from policy statements, newsletters and other media, which were based on reportage of interim findings, expectations, or what was desired rather than the findings themselves. These, when they *were* published, would not have been directly accessible, and were not reported, or only partially reported, in sources that *were* – such as 'Headline Findings' or Concordat documents (DH, 2012a) and various ADASS reports and guidance (some written by a senior Tunstall PLC executive) which were never updated.

Findings do not accord with own experience

Dissonance between evidence and experience was mentioned by several respondents. Although the WSD did have methodological shortcomings, the abandonment of research evidence for anecdote or observational experience ~~shows views of commissioners as being 'in need' of research that they can then use is naïve.~~ In this case study of telecare research adoption, a climate of doubt about the RCT's findings and legitimacy appears to have developed. AQ5

Why would the DH support something that doesn't deliver better outcomes?

This response raises wider questions about the relationship between policy and research. Greenhalgh (2012) suggests:

> Randomised trials, which control for context, have limited purchase for evaluating politically driven eHealth programmes. The Department of Health's cherry picking of unanalysed data to put on its website before the trial had finished recruiting was scientifically inappropriate but politically expedient.

The WSD did not 'prove' what people already know

The survey identified a widely-held view that the WSD would validate positive findings from early telecare project evaluations. Some of this discrepancy may

be explained by various design and methodological flaws in these early studies, but 'upscaling' telecare has also been identified as problematic. Less rigour in the identification of telecare needs and matching these to appropriate technology might be expected in the process of transitioning from project to service (Barlow et al, 2007; Hendy et al, 2012). Other pilot research has also identified poor quality of telecare assessments of need for people with dementia (Leroi et al, 2013). However, the use of research to confirm or verify what is 'known' to be true already (and ignoring research evidence when it does not provide the 'right' answer) may be evidence of the need to consider research receptiveness in debating why some research is not adopted in commissioning practice. This is a complex area but in the UK an absence of research 'culture' in ASCDs, lack of critical appraisal skills, and difficulty in accessing research evidence, and failure to provide updated findings by organisations providing guidance and support to ASCDs, are all potential contributory factors. It was not simply a lack of knowledge about WSD findings that seemed to give rise to doubts about it among telecare managers, but a suspicion or belief that its findings were somehow discredited or untrustworthy. Sources of information available to telecare managers did not engage with the full WSD findings, but continued to focus on encouraging widespread adoption and use and sharing of locally-derived evidence from LA telecare initiatives.

The effectiveness of telecare is still unproven, and there is limited research about cost savings. LA financial commitments to it are considerable, and it would be politically difficult to scale back and review. Telecare is now also being used widely in England based on a belief or hope that it will deliver cost savings and better outcomes, and often as a substitute rather than supplement to 'hands-on' social care, with little apparent concern for the ethical implications of using it in this way (Eccles, 2010; Ganyo et al, 2011).

What difference would it have made if WSD findings had been fairly and widely reported? Firstly, it may have led to LA reconsideration of the impact and value of telecare and scaling back of investment based on evidence from this trial that telecare did not produce better outcomes. Secondly, updating the findings in more publicly accessible documents may also have led to consideration of *why* non-significant outcomes were reported, and deeper scrutiny of the way in which telecare was, and is still deployed, to see if outcomes could be improved. If the general perception is that it 'works', it will not be perceived as necessary to re-conceptualise its use. Telecare services in England have been shaped by PTG funding, policy guidance, and performance indicators. Greenhalgh et al (2016) has suggested that installation of telecare to achieve imposed numerical targets may have downgraded the importance of assessments designed to match devices to need, focusing attention away from the complexities of telecare provision. One outcome is that in the UK (including England) arrangements for assessing people for telecare are claimed to be 'sub-optimal' (Greenhalgh et al, 2016: 3), because the policy focus remains fixed on technological innovation and rapid 'up-scaling' rather than on achieving a better understanding of how existing telecare technologies are adapted and used, and how to best support their use. This reaffirms the importance of establishing whether telecare itself is unlikely to produce cost-effective, positive outcomes for recipients, or whether how telecare services are provided is the key factor.

Conclusion

The findings of the WSD have been generally overlooked in subsequent policy guidance, and widely misunderstood by telecare managers. It is perfectly possible to accept the findings of the WSD without abandoning telecare because although these findings suggest telecare does not 'work' they do not say *why* it does not work. Developing a more nuanced understanding of for whom telecare works, when, and under what circumstances, would be a legitimate response. However, little attention seems to have been paid to ASCD telecare practices, including assessment and commissioning, while at the same time they have been encouraged to commit to, and invest in, telecare. ~~DHSC~~ policy in England remains (uncritically) supportive of the development of LA telecare services. Indeed, the more recent National Health Service (NHS) England new models of care programme include technology 'vanguards' (NHS England, 2016) to better coordinate the delivery of care and support at home. AQ6 AQ7

Our findings suggest that concerns raised in recent qualitative and ethnographic studies of telecare use may be prevalent in English LA telecare services. Attention needs to be paid to assessment activity as a way of improving outcomes; and the amount of funding available for training and staff support relative to the level of investment in telecare equipment may need to be rebalanced. The rediscovery of person-centred rather than personalised approaches to service delivery (Woolham et al, 2015), trusted assessor frameworks (Ballinger and Winchcombe, 2005), or what has more recently been called 'practical reasoning' (Greenhalgh et al, 2015: 9), could support LAs in using telecare more effectively. However, to do so will require significant changes in focus, sanctioned by changes to policy and guidance, with much more attention paid to how telecare can be matched, and adapted, to fit in with the lives of recipients. This might require, for example, thinking of assessment and reviews as recursive processes rather than linear and temporal ones. It is far from clear, in the present financial climate, and in an area where manufacturers and providers are key to the commissioning process, whether this will be possible.

Conflict of interest

The authors declare that there is no conflict of interest.

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AUTHOR QUERIES

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AQ1—not listed in Refs

AQ2—delete?

AQ3—et al ?

AQ4—please expand acronym

AQ5—perhaps this could be expressed more clearly

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